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ABSTRACT

This document describes and discusses aspects of the transition to adult life for people with disabilities in Great Britain and sets it in an international context. The first three sections describe the transition process, the difficulties of implementing a framework for transition, and the aims of the transition process. The aims are the achievement of personal autonomy and adult status; productive activity leading to economic self-sufficiency; equal opportunities for social interaction, community participation, and leisure and recreation; and the development of appropriate roles within the family and of appropriate relationships with others. The next two sections describe the Centre for Educational Research and Innovation (CERI) 1986-89 program of eight studies on disabilities issues and major findings of the "Working Together" program. Among the findings are that appropriate technology can provide affected individuals with access to new opportunities in education and employment, increase their independence, assist their integration into mainstream activities, raise their self-esteem and confidence, and provide needed motivation. The next section addresses the four points on which various administrative reports agree, which are: (1) that fewer youth will be entering the labor market in the next few years, which necessitates making the best use of the new entrants; (2) that preparing the disabled person to exercise choice is necessary; (3) that individualization of programs is the trend; and (4) that quality should be emphasized in programming. Other sections address issues common to both the British and international context, the role of education, and the economic rewards reaped by society when the transition process is successful. The document concludes with 17 references. (CML)

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**Bulletin No. 3**

## The setting

### International

*Since 1978 the Centre for Educational Research and Innovation (CERI), part of the Organisation for Economic Co-operation and Development (OECD), has had a programme of activities concerned with young people with disabilities. It has had two main themes: integration and transition. Transition from school to adult and working life has been the focus of its work since 1982.*

### The United Kingdom

*The United Kingdom has been involved with the CERI transition programme from the outset: in the early years through contributing to meetings and seminars and, from 1989, more actively through 'Working Together?', a project managed by the Further Education Unit (FEU). This programme of activities has made a very significant contribution to the CERI study.*

## The aim of this bulletin

*This bulletin, written by John Fish, consultant to the OECD/CERI Programme, presents and discusses important aspects of the transition process. Its particular focus is the contribution of further and adult education - **working together** with students, parents and other agencies - to the process of transition to adult and working life. The transition of individuals whose disabilities or difficulties may require support for learning is central to the studies. The bulletin summarises the UK contribution, sets it in an international context, and looks at the lessons which might be learned from the CERI programme as a whole.*

*The relevance of contemporary UK reports, such as the CBI study of training needs,* Towards a Skills Revolution[1] *, and the Social Services Inspectorate study,* Day Services for People with Mental Handicap[2] *, are considered, as well as the activities of the Training Agency and the National Council for Vocational Qualifications (NCVQ).*

*The bulletin concludes with a discussion of national and international issues which professionals, parents, services and institutions should consider. Meeting special needs during the transition from school to an adult and working life demands inter-agency collaboration directed towards agreed objectives supported by appropriate facilities and services.*

# Transition to Adult Life

for people with disabilities

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## Transition from school to adult life

Individuals make many important transitions in their lives. Entering school, leaving home, moving from institutions to the community and moving from an active life to an elderly disabled one are some of them. However, the concept of *a process of transition*, and the development of means to support, manage and facilitate the process, are relatively recent phenomena.

The CERI programme concentrated on the transition from school to adult and working life. This transition, important for all, is particularly significant for those with disabilities as it has implications for the quality of their adult life. The activities had two broad themes: the social, psychological and legal aspects of achieving adult status and the educational, training and administrative arrangements necessary for an effective transition[1,4].

Aims, expectations and objectives for adulthood are set by families influenced by the cultural values, policies and practices in individual countries. Although independent living, work, developing family responsibilities and community participation should be accepted as objectives for all, expectations for those with disabilities may differ.

It is not always clear whether society, families or professionals accept the same transitional objectives for individuals with disabilities and by doing so accord them the possibility of adult status. Certainly those with severe intellectual disabilities are often legally excluded from many responsibilities which epitomise adulthood.

## A framework for transition

A conceptual framework for transition is relatively simple to develop but very difficult to realise in practice. Transition should be regarded as a unitary process by which an individual grows through adolescence to adulthood and achieves the balanced state of dependence and independence expected of all citizens.

The complex pattern of different definitions of handicap, and of professional and agency responsibilities during transition, presents young people and their families with problems. For many, an effective passage through the phase may be inhibited by a lack of information, divided responsibilities and unclear objectives.

The objectives of transition for the youth group as a whole are not always seen as appropriate for those who are disabled. Professionals often have explicit or implicit reservations about the extent to which individuals with severe disability might attain the same goals as others.

An important conclusion of the CERI programme is that objectives should be the same for all and that where this much higher expectation exists the objectives are achieved by the vast majority of those with special needs.

The achievement of these objectives may take longer for some individuals and they may require long-term support to sustain them. The handicaps of young people with disabilities should not be increased by preconceptions about the effects of their disabilities on adult life or by placing limitations on their choices and opportunities in the early stages of transition.

## The aims of transition

The aims of the transition process fall into four groups:

- the achievement of personal autonomy, independence and adult status;
- productive activity (i.e. 'working life') leading to economic self-sufficiency;
- equal opportunities for social interaction, community participation, leisure and recreation;
- the development of appropriate roles within the family and of appropriate relationships with others.

Individuals cannot be neatly divided into their health, education, social welfare and employment segments, although administrative arrangements are often based on this assumption. Many programmes still concentrate on one aspect of transition, for example employment or independent living, assuming that other aspects of individual development will take place independently.

## The UK activities

The OECD/CERI programme for 1986–89 included eight specific studies: early intervention, progress towards integration, case management, adult status, new technologies, future employment prospects, individual transition planning and supported employment. Of these, the first two were the subject of separate UK contributions and of other OECD/CERI publications.

The outcomes of the 'Working Together?' programme are being made available, by FEU, in three major studies, two contributory papers and a series of bulletins. Other work associated with the programme, such as the East Midlands Further Education Council (EMFEC) study,

will be published separately. The outcomes will also form part of CERI publications.

## Major findings

The material which follows is a distillation of the major findings of the 'Working Together?' programme:

- the development of adult status;
- new technology;
- preparation and support for employment.

### Adult status

The achievement of adult status was addressed in two studies of self-advocacy: one was part of the 'Working Together?' programme and the other a joint FEU/ EMFEC initiative funded by REPLAN. Advocacy was also the subject of a contributory paper about advocacy and self-advocacy for parents of children and young people with special needs.

In this series of studies, advocacy is the presentation of the young person's needs by parents and others and self-advocacy is a necessary adult skill, involving appropriate self-presentation, which young people should acquire through education and experience.

The first study, by Alison Wertheimer, looks at the effects of developing self-advocacy and adulthood in a small number of families where young people with a range of disabilities were making the transition from school to adult life.

A major issue was the relationship of self-advocacy skills to parental and professional goals for adult status. The interviews in the study illustrate how hard it is for disabled young people to achieve adult status when their parents continue to play such a central role in their lives.

One of the most striking findings is the low level of professional involvement with parents during transition.

Where there was involvement, parents thought that being listened to by professionals, being given a sense of equality and being treated as individuals helped, as did continuity of support from the same professionals. Feeling devalued, feeling blamed for a child's problems and not being understood were negative experiences. Similarly unhelpful were the contributions of professionals who were too directive and did not co-operate with other professionals.

The report concludes with recommendations for action by education, social and health services as well as recommendations for professionals and parents.

The EMFEC study, by Mariette Clare, looks at the development of the self-advocacy skills of unemployed young disabled adults. The project officer supported professionals from a range of agencies as they helped individuals to develop personal portfolios.

These portfolios included an individual history, a diary of activities, a profile of skills and a statement of aspirations. Portfolios established a basis for communication, for building up self-advocacy skills and for self-presentation. The confidence generated by young people's ownership of their own experiences is clear.

The outcomes of the study have an impact on a wide range of professional practices. They illustrate how crucial it is that professionals respect the learner and have the same goals of autonomy and employment for all young people. The importance of proper records, particularly when personal portfolios are developed, is stressed.

Workers developing self-advocacy need considerable support in their work with individuals as the workers' objectives are often difficult for colleagues to accept.

The contributory paper by Phillipa Russell is part of work by the Voluntary Council for Handicapped Children directed towards the effective participation of parents and young people in decision making. It is relevant both to advocacy issues and to inter-agency collaboration.

The issues being explored in the project include parents' feelings about transition, existing models of support for the parents of older children, self-advocacy for young people, the improved co-ordination of services for young people and the professional training necessary to provide partnership and support to both parents and young people during transition.

### New technology

A study by Tom Vincent brings together a wide range of experience in the use of technology to support learners with special educational needs or disabilities and lays the basis for a network of those involved in its development. The current use of technology, illuminated by the first-hand experiences of students and the staff who taught them, was the basis of the study. A summary in the FEU *Working Together?* series, *New Technology, Disability and*

*Special Educational Needs*, explores the issue and a full report of the work has been published as a result of a business initiative by a group of young people[3].

Over 100 people have contributed to the study, including students, college and local education authority staff, social services staff and the staff of specialist centres.

The experiences reported confirm that appropriate technology can:

- provide access to new opportunities in education and employment;
- give increased independence;
- assist with integration into mainstream activities;
- raise self-esteem and self-confidence;
- motivate.

The potential of technology cannot be realised in isolation. New technologies can enable students with disabilities to have a wider choice of courses and curricula and new and enhanced education and employment opportunities, but effective support, in the form of information, advice and technical services, and appropriate training in the use of technology, are necessary for students, their teachers and carers.

However, the survey provided little evidence of evaluation of the matching of new technology to student needs. The complexity of the range of post-school provision, of the differing responsibilities of services and of the needs of individuals requires understanding and then 'facilitation' in dealing with it. The task of 'facilitators' would be to enable students to gain access to adequate information, to advice and to experiences of good practice.

Although it is possible for students to acquire new skills via technology, the opportunity for them to demonstrate those skills during work experience or in employment is less in evidence. Many employers seem unaware of the enabling potential of new technology.

Much progress to date has been the result of *ad hoc* solutions and chance contacts. The absence of any national programme in the post-school sector, or of an information co-ordinating mechanism, has limited what might have been achieved. This needs to change.

The survey suggests that students have made significant contributions to staff development in the area of new technology. Nevertheless, there is a continuing need for training for lecturers and carers if technology is to assist young people with disabilities to the full.

## Preparation and support for transition to employment

Employment is a central feature of adult life for all, and a crucial step for those who are disabled. *Enabled to Work* is a major study of employment possibilities.

The publication also includes a review of education and training opportunities, an example of integrated vocational training for young people who are deaf and a study of the implications of national vocational qualifications for young people with special needs.

The main study, by Matthew Griffiths, reviews the employment situation for young people in the UK. The first section discusses the role of employment in the transition of all young people to adult life and summarises experiences of the additional problems met by those with disabilities. The report goes on to give the perspectives of individuals from agencies concerned with preparation and employment.

There is a traditional three-level concept of employment for those who are disabled: open employment, sheltered employment and diversionary activity. This is now being challenged by the supported employment model.

The report includes descriptions of training and individual case-studies and an important section considers an 'expanded core curriculum'. This would link special needs with those of all young people entering employment. One recommendation is that part of that common core should aim to help young people understand their disability in the context of employment.

Individuals identify points in transition where, in their experience, support or its absence was critical. However, some young people feel that support can often be overprotective and encourage dependence. Support should be flexible, be compatible with an individual's wishes and be phased out in favour of increasing autonomy. There should be a single point of reference for the individual.

Further suggestions include increasing emphasis on:

- developing autonomy in training;
- inter-agency collaboration;
- the development of appropriate models to support transition;
- subsidies for employers in the initial stages of employment.

The report concludes that a thorough exploration of the attainment of adult status is necessary:

'Employment should be a real option ... The primary objective should be to ensure that no form of disability bars anyone from enjoying a normal range of adult experiences including autonomy and responsibility.'

A number of papers which support the main thesis are included in Part 2 of *Enabled to Work*. The pre-vocational and vocational training currently available in England is described by Deborah Cooper, Director of Skill (National Bureau for Students with Disabilities), with particular reference to the needs of young people who are disabled.

A complex pattern of options exists, but it is responding only slowly to the needs of disabled young people.

An initiative concerned with vocational training and job placement for deaf adults is described in a paper by Alistair Kent of RNID and Colin Hickman of Weald College. The paper describes the work of the RNID and in particular its collaboration with a college of FE in the work of a training programme for deaf people which is conducted entirely through signing.

The report summarises the processes involved in this collaboration. The programme is being monitored and evaluated but it is too early to draw conclusions.

The final paper, by Elizabeth McEvoy, describes a two-year project to explore the implications of the NCVQ's developing pattern of qualifications, including equality of opportunity of access to training and qualification.

There will be a move away from qualifications obtained by completing a set course towards certification based on proof of competence to nationally determined standards. New, flexible assessment methods are being considered to allow full certification to be gained over time.

Among the findings to date are the need for greater awareness about the potential of those with disabilities and the need to facilitate their access to training.

A separate contributory paper by Derek Childs describes the support provided by the Open University, in association with other bodies, to students who are disabled. It gives specific examples and concludes that inter-agency co-operation is a particularly important element in the support provided.

## Current considerations

It is significant that approaches to transition, whether concerned with all young people or with those with special needs, agree on a number of points. The CBI report[1], the initiatives of NCVQ, the Social Services Inspectorate report[2] and the OECD/CERI study[3] all, in their different ways, see a changing labour market, empowerment of the individual, individual programmes and quality as significant issues.

### Changing labour market

Smaller youth groups will be entering the labour market in the next few years. As a result there is a concern to make best use of new entrants. Improved possibilities for minority groups, including those with disabilities and special needs, may be possible. If transitional arrangements for them are effective and there is support on entry to and while in work, there may be a new opportunity to establish the value of young people with special needs as employees.

### Empowerment

Empowerment, in the form of vouchers or opportunities for choice, is the second common thread. What distinguishes a 'market' approach from a 'special needs' approach is the recognition that preparation to exercise choice is necessary, together with support, both on entry to employment and to sustain it.

### Individual programmes

Whether the objective is a flexible labour force or the assessment of special needs, there is a move away from inclusive courses, categories and 'all or nothing' packages towards individual programmes and personal profiles for all students, not just those with special needs.

### Quality

Quality or standards are major concerns. Whether stress is on the quality of provision, the outcomes of learning programmes or the effective use of resources, the common focus is improved standards. It does not help those with special needs for their lecturers to be exempted from the standards expected of others.

## Common issues

There are a number of issues whi ch are common to national and international contexts.

### Inter-agency planning and collaboration

The UK is not alone in having traditional areas of

responsibility and means of allocating resources which mitigate against joint planning and collaboration. The aims of different national and local government agencies may be incompatible. Responsibility for individuals may be handed from one agency to another or individuals may be left to find their way through a maze of fragmented information and opportunities.

Although it may be difficult to develop mechanisms for effective co-ordination, it is inexcusable for the agencies concerned not to have agreed aims for transition. Even if contributions are not co-ordinated, agencies should work to common ends. This issue can be tackled and young people, their parents and professionals can contribute.

### Assessment

The 1981 Education Act and the 1986 Disabled Persons Act both require assessment at the end of the school period and look to the preparation of a personal programme as the outcome.

Transitional needs can only be met by assessment which both avoids categorisation and looks at *all* the needs of the individual. It is also important to recognise that, for many of those with disabilities, performance in one situation, such as school, is not always a good guide to performance in real living and working situations.

The starting-point of transition, whether special or regular school, may automatically limit the assessed choices offered to individuals. Further and adult education can offer valuable opportunities for individual self-appraisal and for the reassessment for potential.

### Preparation for an adult and working Life

The CBI report is not alone in putting personal values, integrity and personal and interpersonal skills high on its list of work preparation outcomes. Such preparation should not be confined to the achievement of technical skills, important as these are. A proper balance of academic, vocational and personal skills is widely recognised as necessary.

### Time

Time is an important aspect of transition. How much time is an individual allowed? For how long is education and preparation for an adult working life supported? In a number of countries it is recognised that the transition of those with disabilities may take much longer than their contemporaries so education, training and support is available until the middle 20s.

In other countries, only the able have this amount of time, as they go through higher education, to delay their entry to employment and adult life. If support over time is not available, decreased independence and vocational proficiency result in a long and costly dependent life.

### Supporting empowerment

Professionals and services have to manage the dual, and often conflicting, roles of support and empowerment. Ambivalence in departmental and agency policies and in the aspirations and practices of professionals, together with uncertainty about consumer/client demands, are all factors which work against empowerment. A lack of distinction between disability and handicap, a lack of knowledge about the nature of transitions and uncertainty about goals for those with disabilities all inhibit progress.

Effective transition involves a 'shift in power'. The change, for a professional or parent, from supporting growth and development through childhood to an adult relationship is difficult for many to manage. This is particularly true when the young person's disability involves a significant degree of physical dependency.

### Work with parents

The 'Working Together?' study shows that little professional work with parents is undertaken in the transition phase. Parents have a crucial role to play in preparing their children for an independent adult life. Much work is necessary to develop this role in partnership with professionals. But supporting arrangements for parents and professionals are rarely readily available. Professionals must recognise the importance of parents to effective transition, and policies, planning and training should include work with them.

### Continuity of support

In the UK, as elsewhere, continuity of support for disabled individuals or their families through transition is rare. The development of appropriate mechanisms to initiate and sustain the continuity of support and funding is a problem common to developed societies.

There is a need to provide a single point of reference to young people and their families throughout transition. The 'Kurator' in Denmark is one possible model and the

Advocate another. Further work is needed to ensure an easy, continuous and uncomplicated access to information, advice and support. OECD/CERI will be publishing a study of effective transition management concentrating on the guidance available to individuals as they move from school into adult life.

However, there are also aspects of inter-agency collaboration to develop a progressive and coherent programme for individuals which are emphasised in the DSS report' and in TVEI studies. Informal family and community networks are vital. Service systems developed by statutory and voluntary agencies should support, not supplant, such networks.

### The existence of real choices

Those with disabilities should have the same choices as others, but in practice choice is limited. Choices offered are often linked to expectations and objectives. It is vital to avoid stereotyping individuals according to their disability and to ascertain how far real choices exist for those with special needs and the best ways of making those choices available when they do not exist.

### Transfer of training and experience

This issue is a complex mixture of the fragmentation of individual programmes and the extent to which personal confidence and self-esteem, built up by success in one area of personal experience, is instrumental in increasing overall functioning, self-respect and self-presentation in all areas of life. While it is significant for all young people, it is particularly important for those whose achievements may be limited and whose disabilities make readjustment to new situations difficult.

## The role of education

Although transition is a concern of many statutory and voluntary agencies, as well as of many different professionals, it is of primary concern to young people and their families. Because of this, it is important to be clear about the role of education in the process.

It is important to recognise that many people may be contributing to the education of a young person. In addition to lecturers and tutors in post-school education, parents have a significant educational role, as may social workers and carers. Vocational training staff and employment supervisors also have an educative function. This means that teachers should recognise that educational functions are shared with others. It also implies that all those who have an educational role should:

- work within a curriculum framework with clearly stated aims and objectives;
- develop programmes for individuals within that curriculum framework;
- review and evaluate the delivery of their curriculum.

For example, the care of people with disabilities, particularly severe ones, should include an individual programme to develop and/or sustain personal, social, independence and employment skills.

Increased self-advocacy should be part of the care of people with severe disabilities whatever their age. This 'creative and progressive care' is an important form of education. It is vital if individuals are not to remain expensively dependent.

During transition, education should not be confined to traditional educational institutions. Institutions, and the staff within them, have a contribution to make to education in other settings. Such activities should be an integral part of the response of colleges and institutes to needs in the communities they serve.

Staff, qualified and experienced in meeting special needs, who are skilled in the management of learning and the development of personal programmes, have skills that are now required throughout post-school education. They have much to offer to colleagues in further and adult education and other services and agencies.

There are three major contributions that staff in further and adult education can and should make. They should:

- demonstrate, within colleges and institutes, the highest quality of curriculum development, individual programming, review and evaluation procedures. Teachers with responsibility for students with special needs should have well-developed skills in the management of learning, as well as an understanding of special needs, which permeate the whole work place;
- work closely with other services and agencies to agree aims for transition and to deliver programmes to achieve those aims;
- help the other important post-school educators develop their curricula, their individual programming and their methods of assessment and evaluation.

## Effective transition

The bulletin describes many factors which may facilitate or hinder effective transition and inter-agency collaboration. There is, however, a major perceptual and attitudinal factor which affects all involved and which is crucial to future progress. This is *economic attitude* to disability. Much depends on whether resources devoted to those with special needs are assessed on short-term grounds, with their necessity questioned, or whether resources are recognised as an investment leading to a saving in the costs of lifelong dependence.

There is now evidence, from studies in Sweden and the USA, that any money earned by those who are disabled from supported or subsidised employment is a net gain for the exchequer. Supported independent living also provides a better quality of life at less cost to the taxpayer than pensions and dependent care for life.

Much needs to be done at national and local level to show that investment in effective transition is of long-term benefit both to the individual and to the economy.

## Conclusion

The most significant contribution to effective transition involves a *positive and creative approach to legislation and regulation*. It is possible to see new legislation and regulation in a number of ways. Research shows that implementation varies widely, even where the limits to possible variation are narrowly defined. Good practice emerges from a positive interpretation of the statutory framework associated with a will to make it work for those with special needs. It involves effective joint planning, positive assessment and the development of individual transition plans.

## References


1. *Towards a Skills Revolution*, CBI, 1989.
2. *Inspection of the Day Services for People with Mental Handicap*, Department of Social Services, 1989.
3. *Young People with Handicaps - The Road to Adulthood*, OECD/CERI, 1986.
4. *Disabled Youth - The Right to Adult Status*, OECD/CERI, 1988.
5. *New Technology, Disability and Special Educational Needs: Some Case-Studies*, Vincent, A.T. (ed), Empathy Ltd., Hereward College, 1989.


Relevant FEU publications include:

*Working Together?* a series of studies carried out for the OECD/CERI Disabled Action Programme (1989)

Three major studies:

*New Technology, Disability and Special Educational Needs*

*Enabled to Work: Support into Employment for Young People with Disabilities*

*Self-Advocacy and Parents: The Impact of Self-Advocacy on the Parents of Young People with Disabilities*

Two contributory papers:

*Access to Higher Education: Students with Disabilities at the Open University*

*Self-Advocacy and Advocacy for Parents of Young People with Disabilities and Special Needs*

A series of three bulletins (of which this is the third) describing the inception, progress and outcomes of the Programme.

*New Directions* A curriculum framework for students with severe learning difficulties (1988)

*Transition to Adulthood* A curriculum framework for students with severe physical disabilities (1986)

To be published later in 1990:

*Developing Self-Advocacy Skills* - final report of FEU/REPLAN funded project managed by EMFEC.

For further information about the 'Working Together?' initiative and follow-up activities, or other aspects of FEU's work on special needs, please contact Pat Hood, FEU, 2 Orange Street, London WC2H 7WE (tel: 01-321 0433 ext. 261).

For details of the availability of all the Unit's publications, please contact the FEU Information Centre at the above address.

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